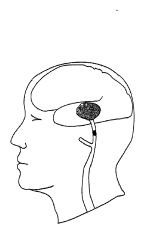
Facts About Stroke and Aphasia

SUBHASH C. BHATNAGAR



Be ma Begar O. Ernasık anır. Burdke Somer

SCOPE of the BOOKLET

Knowing about stroke and aphasia helps families understand the physical and emotional factors that contribute to deterioration in quality of life of the patient. Awareness about these factors can also lead to an increased appreciation of life and familial closeness.

This booklet provides basic information about stroke and aphasia that family members need to know in order to give the best possible care to the patient. It addresses questions such as: What is stroke? How does one get a stroke? How can stroke be prevented? What should patients and their families do after a stroke? How can the family provide the best short- and long-term care for someone who has suffered from a stroke?

To clarify the information provided in the booklet, families are urged to talk with the attending physician.

Aphasia and Stroke Society presents

FACTS ABOUT STROKE and APHASIA

A Guide for Families of Patients with Stroke in India

Subhash C. Bhatnagar, Ph D

Ratna Sagar

Aphasia and Stroke Society

The Aphasia and Stroke Society is committed to promoting care of individuals with stroke and/or aphasia in India through educating the public, training families, and networking stroke victims. It is dedicated to increasing resources that will help improve the quality of life for people with stroke and aphasia.

Society officials and volunteers:

Subhash C. Bhatnagar, Ph D Madhuri Behari, MD Apoorva Pauranik, MD Satish K. Jain, MD M.V. Padma, MD Priti Bhatnagar, MS Rama Pandit, MS Dhanesh Jain, Ph D Brooke Hallowell, Ph D Varun K. Saxena, MD N.M. Reddy, MD Vidyottama Mathur, BA Frank Silverman, Ph D

For more information write to

Apoorva Pauranik, MD 4 Ahilya Puri Residency Club Road Indore 452001 Subhash C. Bhatnagar, Ph D C2B/101 Janakpuri New Delhi 110058 bhatnagars@vons.csd.mu.edu

Madhuri Behari, MD,DM Neurology Department All India Institute of Medical Sciences New Delhi 110029 mbehari@medinst.ernet.in

> © Subhash C. Bhatnagar, 1999 First published 1999 ISBN 81-7070-363-8

Published jointly by Ratna Sagar P. Ltd. and the Aphasia and Stroke Society, this book is available free of charge to stroke patients and their families.

Please ask for a copy by writing to one of the addresses above or to Ratna Sagar P. Ltd. Virat Bhavan, Mukherjee Nagar Commercial Complex, Delhi 110009 Gratitude is expressed to Drs Apoorva Pauranik and Deep C. Jain (for reading the manuscript and many suggestions), Priti Bhatnagar (for the art-work), Manav Bhatnagar (for editorial assistance), Gaurav Bhatnagar (for support) and Byword Editorial Consultants (for editorial support and design).

gar og skale og gar og skale o

This work was supported by the American Institute of Indian Studies.

Contact this author for the aphasia workbooks since these are presently under preparation.

I dedicate this Family Guide
to my father,
who was an inspiration to me.

San Jahren I was married in the Cal

Human Brain and Blood Supply 1

How is the human brain organized?
Importance of adequate blood supply to the brain
Blood supply to the brain

Stroke 4

Types of stroke
Other brain diseases
Who can have a stroke?
Warning signs of stroke
Preventing a stroke

Risk Factors for Stroke 8

Risk factors that cannot be controlled medically Risk factors that can be controlled medically Other factors

Treatment of Stroke 11

Physical Impairments Associated with Stroke 12

Paralysis and loss of sensation Dysarthria (difficulty in speaking) Dysphagia (difficulty in swallowing) Visual problems

Behavioral Changes Associated with Stroke 16

Confusion regarding time and place Inability to control display of emotions Depression Memory

```
Linguistic Changes Associated with Stroke 19
```

Aphasia

Receptive aphasia

Expressive aphasia

Anomic aphasia

Jargon aphasia

Other disorders

Aphasia and recovery

Non-dominant right brain damage

Changes in Lifestyle 24

Returning to Work 25

Rehabilitation 26

Things that the Family Should do to Help a Stroke Victim 29

Things that the Family Should Avoid Doing 31

Ways to be Sensitive to a Patient's Feelings 32

Long-Term Care of Stroke Patients 33

Positioning

Physical exercises

Upper limb exercises

Lower limb exercises

Transfer and mobility

Personal care

Grooming

Dressing

Dysphagia (swallowing disorder)

Eating

Hearing

Seeing

Writing

Thinking

Sensation

Urinary control

Sexuality

Safety in the House 50

In the kitchen

In the bathroom

Helping Patients with Language and Speech Difficulties 54

Dealing with a stroke patient with aphasia

Ways for the family to promote communication

Ways to communicate with a stroke patient

Glossary 60

Pocket Cards 62

Major Regional Medical Centers with Neurological and Rehabilitational Services in India 63



Tor a da hamen beat paretired

The human brain consists of two major parts: the left and right hemispheres. The left hemisphere of the brain controls movement and sensation of the right half of the body, and the right hemisphere that of the left half of the body (Fig. 1). Each hemisphere also regulates different aspects of human behavior. For example, in most individuals the center for control of language functions is located in the left hemisphere while that for musical and spatial—perceptual functions lies in the right hemisphere.

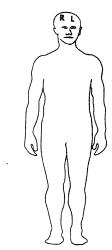


Figure 1. Contralateral sensory/motor organization in the brain.

Brain cells, like all other cells in the human body, need oxygen, which is furnished by the blood. The brain cells cannot store oxygen and, therefore, depend on a constant blood supply. Without adequate blood supply, they can live only for a short time.

An interruption in blood supply to the brain for approximately 5-8 seconds may result in unconsciousness. Sustained interruption for 20-25 seconds can eliminate electrical activity in brain cells and severely impair functions of the brain. Furthermore, an interruption lasting 4-5 minutes results in irreversible brain damage.

Discussing the action

The heart constantly pumps blood to the brain through arteries (large vessels). These large vessels feed into capillaries (smaller arteries with thin walls) which carry blood to the nerve cells.

The pressure of the blood on the walls of the arteries is called blood pressure. This pressure rises and falls approximately 72 times per minute. It rises with each heart beat and falls as the heart rests between beats. Therefore, we have two values expressing the blood pressure, such as 120/90. The higher value represents the systolic pressure which is the pressure when the heart pumps blood into the arteries. The lower value represents the diastolic pressure which is the pressure when the heart rests between beats.

Furthermore, the blood pressure rises and falls depending on what one is doing, whether resting or doing something physically active. These changes in blood pressure are normal. Also, there is a range of blood pressure that is considered normal depending on the age and health of a person. For a young healthy person, the normal range of blood pressure is about 100–140 mmHg (systolic) and about 60–90 mmHg (diastolic).

If for some reasons, blood pressure rises to an unhealthy level and stays there, this condition is called **hypertension**. If left untreated, **hypertension** may damage the brain, heart, and kidneys.

Table 1. Reading of blood pressure

Blood pressure is measured with a sphygmomanometer. The doctor wraps the cuff of the sphygmomanometer around the upper arm. He then pumps air into it and listens to the pulse in the arm with a stethoscope. Blood pressure is expressed by two values: the higher value indicates the pressure when the heart pumps blood into the arteries and the lower value marks the pressure of blood when the heart rests between beats. The normal range of blood pressure for a young healthy person is about 100-140 mmHg (systolic) and about 60-90 mmHg (diastolic).



Stroke is an interruption in blood supply to any part of the brain due to narrowed, blocked, or ruptured arteries. This deprives a part of the brain of required oxygen and nutrition. Subsequently, the affected brain cells die, thereby damaging the brain (Fig. 2).

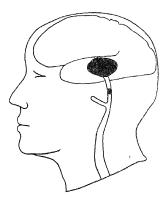


Figure 2. Left hemispheric brain damage in stroke.

In India, stroke affects thousands of people every year and is a leading cause of serious physical and linguistic disability, if not death. However, the exact incidence of stroke is not known. Most stroke patients are elderly individuals (aged 50 years or more) though it can also occur among young people.

Types of stroke

Stroke is characterized by sudden development of neurological symptoms. There are three types of stroke: embolism, thrombosis, and hemorrhage.

- # Sudden loss of vision in one eye or double vision.
- # Sudden loss of ability to speak, find words, and understand others.
- # Sudden onset of unsteadiness, dizziness, or falling without any apparent cause.

These are the symptoms of Transient Ischemic Attack (TIA) or a temporary stroke, which usually disappear within twenty-four hours. A TIA results from insufficient supply of blood to the brain and should be considered a warning or precursor of a larger impending stroke. If you ever experience, or know of someone who has experienced any of these symptoms, consult a physician specializing in brain diseases immediately.

Many causes of stroke can be treated if recognized early in a patient with TIA. Medications available at present can dissolve a blood clot in the brain if the patient is treated within the first three hours after the onset of symptoms. Therefore, consulting a physician immediately after stroke can minimize the loss of physical and linguistic abilities.

Remember that prevention is better and less expensive as compared to seeking treatment after the stroke has occurred.

Proventing a strake

There is no medical cure for stroke. However, stroke can be prevented if appropriate steps are taken early in life. The best way to prevent a stroke is by lowering your own risk factors for cardiovascular diseases. This involves proper medical care of hypertension, elevated blood cholesterol level, and coronary heart disease.

Besides medical treatment, steps that can significantly reduce the risk of coronary heart disease and stroke are cutting down on dietary fat and cholesterol, maintaining proper body-weight, exercising regularly, refraining from smoking and excessive drinking, minimizing stress, and taking a low dose of aspirin daily.



There are many factors that increase the risk of stroke (Table 2). Some are genetic, while others are related to lifestyle. We cannot control genetic factors or factors related to natural processes. However, the factors related to our environment and lifestyle can be controlled by seeking early medical treatment, reducing stress, and making healthy personal choices regarding diet, exercise, and lifestyle.

Table 2. Risk factors for stroke and heart diseases

Cannot be controlled medically	Can be controlled medically	Can be self-controlled
Heredity	Hypertension	Smoking
Sex	Heart diseases	Drinking alcohol
Age	Diabetes	Lack of exercise
Prior stroke	Obesity	Stress

Risk factors that cannot be controlled medically

Age: Older individuals are at a higher risk of stroke.

Sex: Men are at a higher risk of stroke as compared to women.

Prior

Individuals who have experienced a stroke are more likely to have another as compared to those who have

not.

Heredity:

stroke:

The risk of stroke is greater for people who have a

family history of stroke and heart disease.

Risk factors that can be controlled medically

Diahetes:

If the high level of blood sugar or hormonal deficiency in diabetes is not treated, it can cause stroke, kidney

failure, heart diseases, and blindness.

Heart disease: People with coronary heart diseases (heart attack and chest pain) are twice as much at risk of having a stroke as compared to those without a heart condition. Medical treatment of the heart problem significantly

reduces the risk of stroke.

Hypertension: Hypertension is the most common risk factor for stroke. Therefore, controlling hypertension is the single most important factor that contributes to a decline in the incidence of stroke. Incidentally, many people with hypertension are not aware of their condition and those who are aware are not receiving proper therapy.

Obesity:

Obesity, sometimes considered healthy in India, is, in fact, an indication of poor health. Individuals with body-weight exceeding that for their corresponding heights are more prone to experiencing a stroke. A regular regimen of physical exercise, healthy eating habits, and medical guidance can help alleviate this problem.

High level:

High cholesterol level causes deposition of fatty subcholesterol stances on arterial walls, narrowing the passageway. This could lead to heart attack and stroke. Cholesterol in the blood comes from the food we eat. A diet with less saturated fats can help keep our cholesterol level under control.

Other factors

Additional factors that can cause stroke include smoking and drinking excessively, stress, oral contraceptive pills, and inadequate exercise. In India, childbirth has also been found to be an additional cause of (post-partum) stroke in women.

TREATMENT of STROKE

There is no medical cure for stroke. However, medical treatment and physical rehabilitation immediately after the stroke can help patients overcome long-term disabilities. With early assistance, some patients can lead a functionally independent life, while others who retain mild disabilities require minimum supervision.

Medical treatment for stroke is divided into two phases: acute and rehabilitational. The acute phase is directed towards preserving a patient's life, minimizing the effect of swelling in the brain, and preventing another stroke. Drugs are used to control the swelling in the brain and prevent blood from clotting. In some cases, surgery is undertaken to remove blood clots from arteries, drain blood from ruptured arteries, and control bleeding in the brain.

As soon as the acute phase ends, the **rehabilitational phase** begins. It is directed towards limiting the impact of disability and later restoring as normal a lifestyle as possible. During rehabilitation patients are taught how to communicate, walk, and take care of themselves.

Do not expect a miracle. All stories of magical cures are unsubstantiated. Treatment should be followed patiently and all efforts should be made to improve.

PHYSICAL IMPAIRMENTS associated with STROKE

Stroke is often accompanied by many noticeable physical impairments besides aphasia (Table 3). Common physical problems include blindness in half of the visual field (hemianopia), sensory loss in one half of the body (hemianesthesia), paralysis and weakness in half of the body (hemiplegia), paralysis of speech muscles (dysarthria), stuttering muteness, and epilepsy. Other problems include memory loss, attention deficits, and behavioral problems.

Table 3: Common physical impairments associated with stroke

- # Weakness or paralysis of limbs
- # Loss of sensation for pressure, pain, and temperature
- # Paralysis of speech-related muscles
- # Impaired swallowing leading to aspiration of food
- # Inability to see things on the left/right side

Some important physical impairments are discussed below.

Paralysis and loss of sensation

Hemiplegia or hemiparesis is paralysis or weakness in one half of the body. A stroke affecting the left hemisphere of the brain results in the loss of movement (paralysis) and sensation (hemianesthesia) on the right side of the body (Figs. 4A and 4B). This weakness is usually more pronounced in the face, hands and arms than in the legs. Patients with hemiplegia have difficulty in walking, standing, dressing, bathing, eating, speaking, writing, and holding objects.

By teaching specific muscle exercises, a physiotherapist can help the patient walk, dress, and regain movement of the paralyzed limbs. Right-handed patients can also learn to use the left hand for writing. Occupational therapists help patients in using compensatory devices for the activities of daily living.

Dysarthria (difficulty in speaking)

This refers to the paralysis or weakness of muscles in the mouth, tongue, and throat (vocal folds) that help us speak (Fig. 4C). Patients with dysarthria speak slowly and their speech is not very precise.

Speech-language pathologists specialize in communication and can help these patients speak clearly by training them to overarticulate and speak slowly.

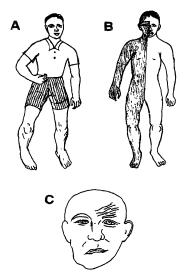


Figure 4. A. Right hemiplegia. B. Sensory loss of the right side of the body. C. Right facial paralysis.

Dysphagia (difficulty in swallowing)

Decreased sensation, weakness, and/or incoordination of the muscles in the oral cavity, face, and pharynx results in dysphagia or difficulty in swallowing. The failure of the vocal folds to come together to protect the airway from the entry of food particles contributes to aspiration or inhalation of food particles. Patients with oral-facial weakness or paralysis have difficulty in holding the bolus (lump of food) together, propelling it to the back of the mouth, or swallowing. This results in food residue in the mouth.

Dysphagia, if not corrected, can result in the aspiration of food into the lungs causing pneumonia. In the case of facial paralysis, the patient has a problem with chewing. The paralyzed side of the face droops and saliva drips from this side.

The radiologist, physician, and hospital-based speech-language pathologist, along with a dietician, can identify the problem in swallowing using videofluoroscopy. This team helps the patient by determining:

- # the texture of foods safe for the patient
- # the amount of food to be taken at one time (bolus size)
- # the best possible position for the patient while eating, and
- # helpful compensatory techniques, such as bending and flexing the head during swallowing.

By incorporating any one or all of these solutions, clinicians and family members can help the patient to overcome problems in swallowing.

In case of serious problems in swallowing, patients may be fed with the help of a naso-gastric tube. This tube has a varying diameter. It is inserted through the nose and runs to the stomach. However, this is only a temporary solution and is used only until the patient can swallow orally.

Families should watch for problems the patient is facing in eating and report them to the doctor.

Some common symptoms of a swallowing disorder are:

- # coughing after eating
- # swallowing only a little food at a time
- # food residue in the mouth after swallowing
- # returning of the food through the nose during swallowing
- # speaking in a gurgly voice after eating

Visual problems

Visual problems include diplopia (double vision) or hemianopia (loss of vision in half the visual field of one or both eyes) (Fig. 5). A person with stroke may not be able to see things on the right side. The best way to help such a patient is by approaching him, and giving him food and medicines from the left side, which is his/her good side.

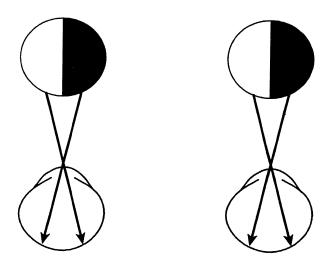


Figure 5. Right homonymous hemianopia.

BEHAVIORAL CHANGES associated with STROKE

Less obvious and non-linguistic changes that occur after the stroke involve behavior and memory. The patient with injuries to the left hemisphere of the brain has greater incidence of depression, grief, anger, and irritability.

Confusion regarding time and place

Patients with injury to the right hemisphere of the brain exhibit a more dramatic change in behavior, and this includes: spatial—perceptual impairment, impulsive behavior, neglect for objects on the left side, anosognosia, and memory deficit.

Patients with spatial-perceptual impairment have difficulty processing distance, appreciating size, following locational directions, reading a map, walking around, and climbing stairs. These patients cannot differentiate between the inside of a cloth and its outside, or between left and right sides. They may not dress the left half of the body and often fail to button shirts and wear clothes correctly. Interestingly, these patients are not fully aware of their impairment.

Inability to control display of emotions

Weak or negative behavior becomes more pronounced after the stroke, irrespective of the hemisphere that has been affected. For example, patients may exhibit a low threshold of tolerance. They may become easily irritated and frustrated. Controlling emotions and anger is difficult for them. At one moment stroke patients can

have a positive attitude, and the next moment, swing to total despair. Small things can cause undue anxiety, and little failures can frustrate them. They may often use asocial words.

These behavioral changes are often a reaction to a situation. These along with changes in the communicative skills affect not only normal family life but the family's social life as well.

Depression

Depression is a medical condition which affects one's ability to cope with life's events in an adequate manner. It can be triggered by any number of causes such as grief over the loss of a loved one, long-term illness like stroke, loss of a job, financial problems, family problems, and the use of certain medications.

Depression is common immediately after stroke. The loss of physical and linguistic independence, suddenness of the illness, and long-term handicaps are the primary causes. Some of the common signs of depression are:

- # Feeling 'down' or sad
- # Loss of interest in activities enjoyed earlier
- # Loss of interest in previously important relationships
- # Decreased energy level and slowed movement
- # Frequent complaints of bodyache and malaise
- # Significant weight loss/gain without change in appetite
- # Sleeplessness especially in the early morning
- # Decreased ability to concentrate and take decisions
- # Recurrent thoughts of death or suicide
- # Extreme preoccupation with past failures and guilt.

While none of these symptoms in itself is significant and some depression is normal; most of us have experienced one or more of these at different points in life. However, these signs are clinically important if they occur simultaneously and last for 3–4 weeks or longer. Depression can be effectively controlled through

medications. Thus, if these symptoms persist it is important that the patient's family seeks medical help.

Depression is more likely to occur among those who do not talk about their sickness or do not have someone to talk with. Talking with a psychologist or people with similar stroke-related experiences may help in dealing with feelings of unhappiness and despair. What the family can do is sit with the patient and be friendly in a matter-of-fact way, try to help the patient understand that there is treatment available for his/her sufferings. However, the family should make a note of the following:

- # Do not ignore the patient
- # Do not be overly cheerful
- # Do not criticize the patient
- # Do not get angry with the patient, and
- # Do not sympathize and tell the patient that you feel the same way.

Memory

Almost all brain injuries affect memory and attention to some extent. Usually, old memories are preserved but learning something new becomes difficult after stroke. Patients may forget simple things like buttoning a shirt, folding clothes, and tying a knot. Initially, the patients may not recognize familiar faces, or may forget things that might have happened only hours before. They may not even be able to recall names of family members, and face problems with numbers and simple calculations and learning new information.

Brain damage may also affect attention. Patients may find it difficult to attend to tasks, focus on the conversation, and are easily distracted. They are in and out of conversation and may process limited information. Small distractions such as the television, phone, one's arrival and departure, a small noise, crying and talking can make it impossible for them to focus. The best way to help patients is by eliminating distractions and conversing in a quiet place.

LINGUISTIC CHANGES associated with STROKE

Aphasia

Aphasia is an impairment in the ability to use language after an injury to the brain, where the patient cannot express himself/herself and/or understand others. Stroke/cerebral vascular accident—where one of the arteries of the brain may have a clot or hemorrhage—is the most common cause of aphasia. Other diseases that cause aphasia are brain injuries caused by tumors, trauma, and infections.

Aphasia impairs different language functions in different ways. This explains why there are different types of aphasia (Table 4). An aphasic patient can experience difficulty in one or many language functions, such as comprehending written and spoken language, writing, and speaking.

Patients with aphasia find that little around them makes sense. People talk around them but their speech is meaningless like a series of noises. Numbers and letters do not look the way or mean what they did before the stroke. They can see written words but these appear to be a meaningless sequence of lines. Patients pick up pens but do not know what and how to write. Patients know what they want to say, but the words they use are incorrect. As the patients have to depend on the family for complete care, this loss of independence may cause depression.

Table 4: Common types of aphasia

Types of aphasia Clinical characteristics

Receptive aphasia Understanding is reduced (limited) while

speech is fluent though meaningless

Expressive aphasia Understanding is preserved but the ability to

speak is limited

Anomic aphasia Impaired word-finding ability

Jargon aphasia Using meaningless words

Receptive aphasia

In receptive aphasia, patients do not understand and cannot relate words with their appropriate meaning (Fig. 6A). They might hear things quite differently from what was said. They may require a great deal of effort and a long time to process spoken language, think, and prepare a response. However, in order to make themselves socially acceptable, they may nod and smile to make it appear that they have understood everything.

Expressive aphasia

In expressive aphasia, the patient's ability to communicate verbally is impaired (Fig. 6B). The extent of the impairment varies from patient to patient. Some patients may speak imprecisely due to muscle paralysis (dysarthria); some may not be able to recall words to say anything; some may speak in disjointed one-word sentences; while some may have difficulty in retrieving and forming words and consequently, produce garbled speech.

Anomic aphasia

Anomia is a common aphasic symptom. In anomia, patients find it difficult to retrieve the names of objects and people (Fig. 6C). Aphasics either cannot remember names or cannot recall desired words. Therefore, they either may not speak while searching for the word or may produce an inappropriate word. In case they are unable to recollect the right word, they may talk around the word, using words that only loosely relate to the intended word.

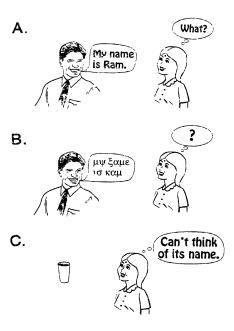


Figure 6. A. Receptive aphasia. B. Expressive aphasia. C. Anomia.

Jargon aphasia

In jargon aphasia, the patient has a marked problem with the correct choice of words and may also invent new words without realizing it. The patient speaks fluently using a full range of sentences with normal syntactic structures but these do not make sense to others.

Other disorders

Apart from the above-mentioned problems, disorders of writing and reading are also associated with aphasia. The patient may not be able to spell words and write sentences. The patient may not be able to match written letters with their sounds and understand the meaning of sentences. The patient may not be able to do mathematical calculations.

No two aphasics are alike and, therefore, no two individuals ever show identical language difficulty. Some aphasics show mild problems, while others have moderate to severe difficulty. One should not confuse language impairments due to aphasia with the loss of intelligence. The patients have not lost the ability to think and reason, though initially they may appear confused and unaware of their surroundings.

Aphasia and recovery

In the beginning, it is difficult to assess the extent of permanent damage and, hence, to tell how much of the ability to communicate will return. This is because trauma to the brain causes brain tissues to swell, and it can take several months for the swelling to subside and for impaired tissues to heal.

Usually, there is some recovery in the ability to communicate. Many who show aphasic symptoms may recover within a few weeks. Others may take 3–6 months. If aphasic symptoms persist for 5–6 months, the patient may not recover completely.

Speech therapy can facilitate language recovery in aphasics. It involves a carefully designed exercise programme. Speech–language treatment takes time and must be continued for months. It may require participation of the family for years. Speech therapy is most effective if provided immediately after the stroke.

Non-dominant right brain damage

In right-handed individuals, the right hemisphere of the brain processes non-linguistic functions, such as visual and spatial concepts, music, and emotions. Stroke patients with right hemispheric lesions present an atypical clinical picture.

The behavioral problems associated with non-dominant right brain injuries are: impaired ability to recognize faces, draw or design pictures, follow directions, orient themselves in space and time, attend to the left half of the space, and dress the left side of body. These patients are verbose but they neither convey much information nor do they directly answer questions.

They are also not sensitive to emotions. As a result, they are not able to understand emotional language, comprehend facial expressions or express emotions while speaking so their speech is usually flat. With impaired ability to process emotions, they often make inappropriate comments and exhibit apparent lack of concern for others. The patients also have difficulty in arranging their thoughts sequentially.

CHANGES in LIFESTYLE

One of the most dramatic impacts of stroke is on a patient's lifestyle. Stroke victims depend on their family for their basic communicative and physical requirements. The loss of ability to communicate and behavioral changes make it difficult for the patient to return to work and affect the family's ability to remain socially active. If the individual was the bread-earner of the family then his/her inability to resume this role affects the entire family. This necessitates a role-change in the family, where the spouse or children have to take on more responsibilities.

Adjusting to changes in lifestyle is stressful for both the family and the patient and this often leads to frustration. Speaking openly about frustration and sharing feelings with others with similar experiences has been found to help. Talking about changes in lifestyle with trained professionals can also help cope with the tension resulting from the behavioral and physical changes.

RETURNING to WORK

Unfortunately, the majority of stroke patients do not return to work because most jobs require good language skills for effective communication. Stroke patients with only mild language impairment are able to return to work. There are many factors that affect one's ability to return to work: (1) How well can the patient communicate? (2) What are the skills needed for the job? and (3) How supportive are the co-workers of the stroke patient?

In general, re-employment of stroke patients involves two steps. The first step is to reorganize or reduce work-related responsibilities to match the functional capacity of the patient. If this is not practical, the patient may be trained for another available job in the organization which he/she can do with or without supervision.

In addition, superiors and co-workers must be considerate and should understand the patient's disabilities as well as abilities. The supportive attitude of the co-workers along with their understanding of the patient's limitations can help the patient perform adequately on the job, promote his/her self-esteem, and save the patient's family from a financial disaster.

REHABILITATION

Once stroke has occurred, there may be some spontaneous recovery of lost functions. This begins within a few weeks and may continue for six months before slowing down. Factors that contribute to natural recovery after stroke are the development of alternate channels of blood circulation, restoration of function in partially impaired brain cells, and functional reorganization in the brain. Not all stroke patients show similar recovery. Some show greater spontaneous recovery within a few months, while others are left with serious physical and communication problems.

Rehabilitation is the most important avenue for patients, particularly for those who will not completely recover on their own. The primary goal of rehabilitation is to improve the quality of life of patients by teaching them ways to overcome physical disabilities and promoting channels of communication. Rehabilitation involves a team effort under the supervision of a physician and includes physical therapy, occupational therapy, and speech therapy.

Physical therapy

Physical therapy is important for retraining the paralyzed muscles. It also prevents atrophy and weakness in unaffected muscles. Physical therapy also helps aphasic patients become independent in walking, standing up, and sitting down.

Occupational therapy

Occupational therapy improves a patient's self-reliance in daily activities so the patient can feed, dress, bathe, and take care of toilet needs.

Speech therapy

Speech therapy is very helpful for aphasic patients as it helps them speak and understand better. It consists of structured speech and

language exercises, which are developed and supervised by a speech pathologist.

Complete rehabilitation services are available only at large regional medical centers in the country; some of these sites are listed at the end of this booklet. The family needs to contact these hospitals to avail of the services, find out if there is a fee for such services and if they can afford it.

Three important aspects of rehabilitation are early rehabilitation, patient's motivation, and support from the family.

Early rehabilitation

Rehabilitation (speech, physical, occupational) is most effective if it is started immediately after the stroke. Early rehabilitation begins with instructions to prevent the progression of disability. Examples of such instructions are limb manipulations, muscle exercises, and joint movements that improve blood circulation and prevent further movement disabilities. Promoting the importance of communication through speech, gestures, and communication boards helps patients to express themselves.

Patient's motivation

A patient's desire to improve and his/her dedicated participation in rehabilitation perhaps plays the most significant role in physical and language recovery.

Support from the family

The support of the family is another important factor for long-term recovery. This is especially important in the case of bedridden patients. Family members can help by encouraging and motivating the patient. Patients with good family support and an active social life derive maximum benefit from rehabilitation.

Families and patients must know that there is no miraculous treatment for stroke and aphasia. Nothing can replace the importance of the three above-listed aspects of rehabilitation. Wandering from hospital-to-hospital and doctor-to-doctor in search of a cure does not help.

THINGS THAT the family should do to help a STROKE VICTIM

The following are a few common suggestions for the family to help a patient improve his/her communicative and functional skills:

- 1. Learn about stroke and aphasia.
- Accept the patient's limitations in terms of what he/she cannot do.
- 3. Make sure that the patient is always under a neurologist's or a physician's care. If you cannot locate one, go to the District Hospital, which is managed by doctors who know about strokes or will refer you to a specialist. Also find out about available rehabilitation facilities at the Civil Hospital.
- 4. Seek medical, physical, occupational, and speech treatment as soon as possible after the stroke.
- 5. Promote every opportunity for the patient to communicate. Encourage the use of number counting, recitation of days, or greetings like 'namastey' or 'jai hind' or 'baithiye'. These are automatic responses and are usually easier for the patients to say.
- 6. Praise the patient's successful attempts regardless of how small the achievements.
- 7. If medically permitted, keep the patient occupied with family and social activities.
- 8. Make efforts to keep the patient on a routine. This provides security and promotes confidence in his/her ability to function.

- 9. Ensure frequent rest periods for the patient. Generally, stroke patients perform better after they are rested. The family must use the time after rest to work on language and speech activities.
- 10. Remember that the patient is an adult. Treat him/her as a mature individual and as an indispensable family member. The patient should be a part of all important decisions just as he/she was before the stroke.
- 11. Be sensitive to the patient's needs. Stroke patients may not like to see friends and relatives if they have not adjusted to their impaired communicative ability. Honor their desires and introduce them to social interactions gradually.
- 12. The patient may often use profanity. This is an automatic response and the patient may not have control over it. Accept this behavior without showing any anger or amusement.
- 13. If the patient begins to cry for no apparent reason, ignore this behavior and change the task.

THINGS THAT the family SHOULD AVOID DOING

- 1. Do not feel sorry for the patient. Feeling sorry will only affect the patient's self-confidence.
- 2. Do not speak or volunteer to speak for the patient unless the patient asks or unless it is required.
- 3. Do not readily supply a word to the patient if you cannot get a response. Supply a word only to minimize the patient's frustration.
- 4. Do not ask the patient to do things which he/she is unable to.
- 5. Do not insist that the patient speak the correct word or sentence. Such insistence will only cause frustration.
- 6. Do not discourage the patient from communicating regardless of how he/she does it (speaking, gesturing, or writing).
- 7. Do not offer false hope of cure to the patient.
- 8. Do not keep the patient away from family and friends.
- 9. Do not be discouraged if the patient cries. Crying is a natural form of expression.
- 10. Do not ignore the patient while conversing with others.

WAYS TO BE SENSITIVE to a PATIENT'S FEELINGS

- 1. Treat the patient as an adult with dignity and respect. The patient is the same individual as before. He/she has the same desires, emotions, and concerns and needs the same love, attention and care. The family should continue to treat the patient as an indispensable member.
- 2. The patient should be kept informed of what is happening in the family and be included in all decision-making.
- 3. Respect the patient's right to privacy. The patient should not be forced to socialize against his/her wishes.
- Be aware of the patient's physical tolerance and fatigue.
 The patient is most ready for treatment and socialization after a good rest.
- Patients often understand more than they can speak.
 Therefore, do not discuss anything concerning the patient in his/her presence.
- Always be cheerful. Given the tension in the family, it may
 be difficult. However, persistent cheerfulness has a positive
 impact on the patient's attitude. A patient's positive attitude
 is very helpful in recovery.
- 7. Be sensitive to the handicaps that result from hemianopia, hemiplegia, and loss of sensation.

LONG-TERM CARE of STROKE PATIENTS

After the stroke, life changes completely both for the patients and their families. In the acute phase of the illness, patients may suffer from depression because of their physical and linguistic limitations and loss of independence.

The primary purpose of long-term care is to make the patient as independent as possible. With the limited availability of rehabilitative facilities in India, the major responsibility for care falls on the family.

The family must remember that there is hope. Patients can achieve some degree of independence and return to many of the earlier activities through consistent efforts and guidance. This may involve reorganizing family life and relearning different steps to overcome difficulty. The family is responsible for taking the patient to and from the rehabilitation center or hospital for daily sessions.

Unfortunately, only a few hospitals in the region provide complete rehabilitation to stroke patients. Private rehabilitation facilities may be beyond the financial reach of the average patient. Subsequently, the financial burden of a patient's rehabilitation largely falls on the family. In this context, here are a few suggestions which explain the concept of long-term care and help the family participate in the process so that the patient can regain functional independence.

Positioning

Since stroke patients may be unable to turn in bed by themselves, they often get pressure sores (bedsores) on the body from lying in the same position. For the patient's comfort, therefore, it is necessary to frequently turn and reposition him/her.

- # Do not let the patient sit or lie down in one position for more than an hour. He/she should be turned and repositioned frequently. Use a pillow or soft cushion to relieve pressure on bony areas. This will help prevent bedsores and muscle/skin pain.
- # Changing the positions where pressure is applied also promotes blood circulation and increases sensation in the limbs.
- # If there is any redness or pressure sore on the skin, it should be allowed to heal before pressure is applied on that part of the body.
- # If sitting is the primary position for the patient, he/she can first lean to one side and then to the other. Alternatively, he/she can periodically lean forwards to relieve the pressure on the buttocks.
- # Try having the patient grasp a rope that is secured to the center of the foot of the bed and raise himself/herself. This will help the patient independently sit/stand upright.

Physical exercises

Physical exercises are important for strengthening the limbs and preventing shrinkage or atrophy of muscles. Consult a physiotherapist as he/she is best trained to prescribe the right kind of exercises for the disability. Massage is of minimal use in strengthening muscles. The following information may be useful for the family (Figures 7 and 8):

Upper limb exercises

The arm regulates the position of the hand and its movement.

The following exercises are useful in strengthening the arm:

Shoulder flexion: Move the arm upward to touch the

top or back of the head.

Shoulder abduction: Move the arm away from the body.

Shoulder extension: Move the arm backward with or

without assistance to touch the back

pocket.

Elbow flexion/

Bend and unbend the elbow.

Forearm exercise: Move the arm upward (supination)

and downward (pronation)

alternately. Also rotate the forearm

inward and outward.

The patient can also passively move the paralyzed arm with the hand of the other arm.

The primary function of the hand is to grasp, release, and manipulate objects. The following exercises are recommended for increasing the control of the hand:

- Move the wrist upward and downward while holding a small object.
- ▼ Move the palm upward and downward alternately.
- ▼ Move the thumb in all directions.
- ▼ Bend and unbend the fingers.
- ▼ Keeping the hand straight, point the fingers to all directions: forward, backward, and laterally.

Lower limb exercises

Hip and knee: Extension and flexion

Hip flexion with knee extension

Abduction and adduction of hip

Knee: Extension and flexion

Ankle: Dorsiflexed (flexion: pulling the ankle up)

and plantar-flexed (extension of ankle)

Toes: Extension and flexion.

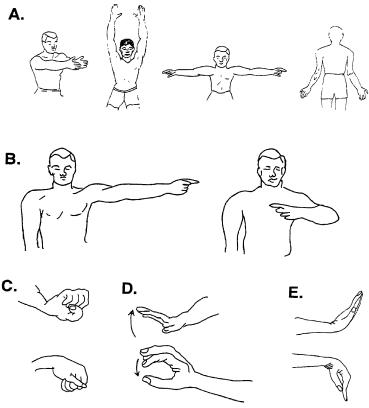


Figure 7. Suggested physical exercises for the upper limbs.

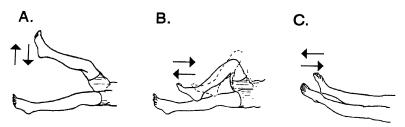


Figure 8. Suggested physical exercises for the lower limbs.

Make the patient stand against the wall with arms extended straight in front. This may strengthen the elbows. Make sure that the wrists do not slide down as this may hurt the patient.

Transfer and mobility

For individuals with limb paralysis, even basic movements are difficult. These include moving or transferring from one location to another, or simply moving from the chair to the bed or toilet. Physiotherapists are the best trained to teach the correct ways of movement and transfer.

The following suggestions can help to increase limb strength:

- # Exercising the following under the constant guidance of family members would improve the patient's control over his/her weak side:
 - ▼ standing straight
 - ▼ gradually transferring weight laterally
 - walking on the knees taking a few steps backwards and forwards
- # Prior to transferring from one place to other, the patient should trial lift from a sitting surface or mentally practice getting up.
- # The surface which one is transferring from and the surface one is transferring to should be secured. These should also be at the same height and as close as possible. Wheelchair brakes should be on or the surfaces secured next to a wall.
- # For a standing or sitting transfer, first lead the stronger side of the body and then move the other one.
- # Usually, patients with paralysis have enough strength in one or both legs to support their weight. They can do a standing transfer.

- # A sitting transfer is recommended when both legs are paralyzed or amputated.
- # Always secure a strong leather belt around the patient's waist. A helper can hold this belt in case the patient falls and protect his/her head from getting hurt.
- # Always maintain a wide base of support for the patient while he/she is standing.

Personal care

Stroke patients with right hemispheric lesions may often ignore one side of the body. They may even ignore food offered from and persons present on their weak side. The following suggestions could be helpful for the family in overcoming this difficulty:

- # Increasing awareness of the weak side by making the patient look and perform activities on that side.
- # Talking to the patient while sitting on his/her weak side or moving to this side from the strong side.
- # Passing food or other items from the weak side and talking to make the patient aware of the activity on the weak side.
- # Helping the patient identify body parts on both sides: first on the strong side and then on the weak side. For example, you could ask the patient to show you the right/left ear/hand/knee. You could also ask the patient to tell which part of the body is touched.

Grooming

Basic physical hygiene of the patient should be maintained. This affects the patient's self-esteem. Here are a few practical suggestions:

- # When at home, the patient should wear regular clothes. Do not clothe him/her in a night dress during the day as it makes one feel ill.
- # Help the patient apply make-up if she wears it.
- # Make sure that the patient brushes his/her teeth every day.
- # If the patient cannot shave, have a family member or barber shave him at least once or twice a week.
- # Keep the nails of the patient trimmed. If the nails are dry, soak the fingers in warm water. This will soften them before trimming. One way to trim nails is to fasten fine sandpaper on a table and run the nails over it. If the patient has diabetes, do not trim nails short.
- # Keep the patient's genitals clean. In patients with paralysis, it is easiest to clean the genitals when they are lying down.
- # After a shower, dry the patient's body. Also apply lotion/oil to prevent the patient's skin from drying.

Dressing

Dressing requires familiarity with the steps involved. The occupational therapist is best trained to assist in this activity. Common practical suggestions for the patient are:

- # Use clothes that are loose and open in front. Use clothes that slip easily instead of polyester clothes that stick to the body.
- # Before dressing, place all the clothes in the order you plan to put them on.
- # For wearing trousers (Fig. 9), the best position is to sit on a chair or stool. First insert the weak leg in the opening and then the strong one.

- # For wearing a shirt (Fig. 10), sit on a chair or stool. First insert the weak arm in the sleeve and then the strong one. Then bring the opening to the proper position for pushing the head through.
- # For undressing, first pull the strong arm/leg out of the sleeve/ opening and then the weak one. Then pull the sweater/shirt over and off the head. This is a difficult step and one should devote time to it. Do not panic when the head is covered with the sweater/shirt.
- # Carefully select clothes with elastic waistbands, pull zippers, button hooks, and velcro closures. These are simpler to handle.
- # Wear shoes without shoelaces. A long-handled shoe-horn would help. This can easily be made by a skilled carpenter or by welding an aluminum rod to the shoe-horn.

Dysphagia (swallowing disorder)

Stroke patients often have problems in chewing and swallowing. These result from lack of sensation, weakness and/or incoordination of muscles in the oral cavity, face, pharynx, and larynx. Food falling into the airways can cause choking and lead to aspiration pneumonia.

Here are some practical suggestions that will help patients experiencing problems in swallowing:

- # Family members must learn the first aid required to clear the airway if the patient chokes on food (Fig. 11).
- # First aid for choking in a standing or sitting person requires the helper to make a fist, place it (thumb side) against the victim's stomach below the rib-cage and above the navel, grasp the fist with the other hand, and press it into the patient's stomach with quick upward pushes (Fig. 11A). Repeat the push until the object is cleared.

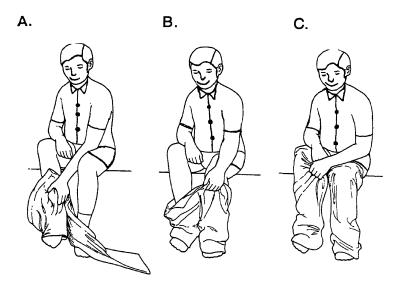


Figure 9. Dressing techniques for hemiplegic patients: pants.

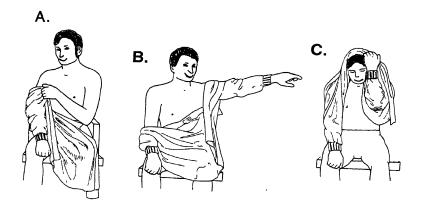


Figure 10. Dressing techniques for hemiplegic patients: shirt/kurta.

- # For a person lying down, first aid involves first placing victim onto the back and facing him/her in a kneeling position before pushing the victim's abdomen with upward quick pushes with the heel of hands (Fig. 11B).
- # The texture of the food is very important. The family should try different soft or regular foods to see which foods are not aspirated and are simpler to eat. Soft food or food made into a paste is usually easier to swallow for patients with paralysis of facial and throat muscles.
 - Use a grinder/blender or a *sil-batta* to break up food. Halua, dals, idali, mashed potatoes, khichri, and bananas are a few soft Indian foods. If the patient aspirates these, the family may try regular food which is not soft.
- # Start with a small amount of food (bolus size) such as ¹/₄-¹/₂ teaspoon. This can be increased if there is no problem in swallowing.
- # In case of paralysis of the tongue, place the food on the stronger side of the tongue. This helps in chewing. Placing food at the back of the oral cavity can also help.
- # Exercises of the tongue and lips can also help patients with oral paralysis.
- # Allow plenty of time for chewing and swallowing.
- # Encourage patients to swallow twice for every bite.
- # Ask patients to clear the mouth and throat after swallowing to prevent the accumulation of food. This will prevent choking.
- # Using cold spoons and cold foods has been found to be helpful in patients who lack sensation in the oral cavity.
- # If the patient uses dentures, eyeglasses, hearing aid, and/or any other neck-support devices, he/she should continue to use these while eating. Make sure that dentures are properly cleaned and placed properly in the mouth.

A. B.



Figure 11. First aid for choking:
A. Standing or sitting.
B. Lying down. (Based after American Heart Association)

The following positions are also helpful while eating. The family should see which of these work for the patient and which of these he/she can remember while eating:

- # Lowering the head (chin to chest) while eating helps the patient by widening the base of the tongue.
- # If the patient has a problem with chewing, tilting the head back causes gravity to move the bolus to the back of the oral cavity and transfer it through the pharyngeal cavity.
- # If the patient has a problem with chewing on one side, turning the head to the affected side closes the weak side of the pharynx. This forces the food to go to the strong side of the pharynx.
- # Turning the head to the strong side moves the bolus to this side and prevents food from being trapped on the weak side.

Eating

The following may help the patient while eating:

- # Using a thali with guards (Fig. 12A). This prevents food from falling off the plate.
- # Using cups with a wide rubber base (Fig. 12B). These are sturdy and easier to use for patients with paralysis.
- # Using a spoon with a wide handle (Fig. 12C). You can increase the width of the handle by having a piece of metal welded to the spoon.
- # Sitting on a chair next to a table that comes up to the patient's chest. Placing both elbows on the table makes eating simpler.
- # Rolling the chapati and soaking it in vegetable/dal gravy. This softens it and makes it simpler to chew.
- # Eating foods with soft texture. These are easy to chew.

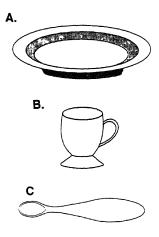


Figure 12. Modified utensils: A. Thali. B. Cup. C. Spoon.

Hearing

Stroke generally does not affect hearing. Any problem in hearing could be due to normal age-induced hearing loss (presbycusis).

For the hearing problem alone, one should consult a certified audiologist. However, if the patient also experiences ear-discharge and earache, the family should consult an ear, nose, throat (ENT) specialist.

Seeing

Visual problems commonly occur after a stroke. These affect the patient's ability to carry out daily tasks. The most common problem is hemianopia which is the loss of vision in one half of the visual field (left or right) of one or both eyes. Individuals with right hemianopia ignore objects placed on the right side, do not read the right side of the page and do not even dress their right sides. While moving around, they bump into furniture, walls, people, and doors.

The following could be helpful for patients with right hemianopia:

- # Train the patient to habitually turn his/her head and look to the right side.
- # Remind the patient to attend to the right side. Moving objects from left to right and right to left can also help in increasing the awareness of the patient.

Writing

The following may help the patient while writing:

Positioning papers on a clipboard while writing. This will prevent the paper from slipping.

- = Using a pencil or pen holder. This gives support to the fingers while writing. This device can easily be made at home using one-inch wide elastic measured to fit around the thumb and index finger (Fig. 13A).
- # In case of paralysis of the right hand, encourage the patient to write with the left hand.

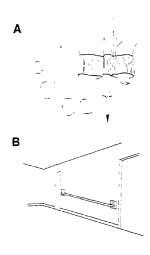


Figure 13. Modified environments: A. Pencil holder. B. Handrails.

Thinking

Injury to the brain may also affect the patient's ability to think clearly, especially when it involves processing multiple information before making a decision. This could be very frustrating when the patient tries to solve problems.

The following could help the patient to overcome problems in thinking:

- # Making sure that the patient is well-rested.
- # Always conversing in a quiet place.
- # Step-by-step directions make it easier for the patient to complete the task.
- # Step-by-step description of the activity by the patient also helps him/her to be precise.
- # Practicing the same activity over and over can help the patient to perform the task correctly.
- # Accepting the fact that even routine things could take more time.

Sensation

The stroke patient may not be able to feel pain or variation in temperature on the weak side. He/she may experience a burning or tingling sensation and pain if touched on this side. The loss of sensation poses a threat to the patient's safety as he/she can get burned.

The following may be helpful to the patient in avoiding accidents:

- # Touching the object with the strong side or asking someone to check its temperature before you handle it.
- # Using some form of potholders when working near the stove. Using stabilizers for handling hot pots and pans.

Urinary control

Many stroke patients have problems with urination. Those who cannot control their bladder movements also have difficulty

controlling their bowels. They may exhibit diarrhea-like problems. Problems associated with urination generally subside with recovery.

The following may be helpful to the patient in reducing problems associated with urination:

- # Visiting the toilet regularly every two hours.
- # Visiting the toilet after every meal and before going to bed.
- # Regulating the intake of fluids after 7 o'clock in the evening. This controls the frequency of visits to the toilet and urinating in bed at night.
- # Keeping a bedpan nearby can further minimize the inconvenience of walking to the toilet.
- # Keeping a bell nearby to alert the family for help at night.

Sexuality

Sexual pleasure plays an important role in happiness in life. It is, however, the least talked about subject in the rehabilitation of stroke patients.

Stroke patients experience a lack of interest in sex for some time. This could be because of depression, and/or distorted self-image due to impairment, or the effects of prescribed medications.

Individuals who were sexually active before the stroke can continue to be so. Neglecting sex may cause unnecessary tension and emotional conflict. Sexual participation after stroke may, however, require physical adjustments since paralysis and loss of sensation in the limbs interfere with sex.

Concerns associated with resuming sex are: worry of having another stroke during sex, fear of rejection, and anxiety regarding failure to perform. Further, fear of failing to perform can cause embarrassment to the patient and affect his/her self-esteem. Therefore, the patient and spouse should have an open discussion

with the attending doctor. The doctor would be the best person to advise on satisfying sex.

If the patient is a woman of child-bearing age, consult the physician about family planning, physical effects of pregnancy and the risks that may be involved. Speaking with the physician can help the patient and spouse. The patient should also consider her ability to care for the baby.

The following may be helpful to the patient and spouse:

- # Since physical attraction contributes to sexual desire, it is important that the patient maintains physical hygiene and proper grooming. This will help him/her remain attractive.
- # Both partners should share what they feel and openly discuss the physical adjustments in terms of important positions to compensate for paralysis and loss of sensation.
- # It is of utmost importance that both partners plan sex when they are well-rested and have enough time.
- # Minimize distractions and interruptions during sex.
- # Create a stimulating environment which induces relaxation, such as pleasant music.
- # In case the patient cannot perform intercourse, the spouse and the patient may examine the alternatives to sexual intercourse. Kissing, hugging, touching, appearing attractive, and feeling intimate could be important alternatives to expressing and enjoying love.



Safety is the single most important issue after the patient returns home. The following are suggestions for the family/patient which may help him/her live safely and participate in self-care with minimum assistance:

- # Give the patient a bell which he/she could use to seek help when needed.
- # If you have a telephone, keep the emergency numbers near the phone.
- # If the patient lives alone or with an elderly spouse, arrange for someone to visit or call him/her once a day.
- # Install a rubber cushion shoulder cradle for the telephone.
- # Install handrails or some support in areas where the patient walks independently (Fig. 13B).
- # If there is a threshold (door chaukhat) at the entrance, have it removed as it poses problems in his/her movement.
- # Make one of the aids for walking available at home as recommended/required.

These include:

- ▼ tripod stand
- ▼ adjustable aluminum walking sticks
- ▼ walking frames
- ▼ adjustable elbow crutches

Consult a physiotherapist to find out where you can get these in your area.

- # Take steps to eliminate the hurdles that stairs pose in the house. Either keep the patient confined to the area where there are no stairs or install a ramp. This will help the patient use a wheelchair at home.
- # Remove all movable things from the floor to create a wide area for the patient to move about freely. Avoid using carpets, furniture, and cluttering walkways.
- # Always use beds with a low height. This will prevent injuries from any accidental fall.
- # Place a foot-rest to support the patient's feet while he/she is sitting. This would relieve pressure from behind the knees (Fig. 14A).
- # Stroke patients find mirrors which fit around the neck easy to use.

In the kitchen

- # Install raised kitchen counters to facilitate working.
- # Keep the kitchen items and utensils within easy reach and low on the shelves. This would help the patient while cooking.
- # Keep cooking utensils with long, wide handles.
- # Use a thali with high guards. This prevents food from falling off the plate.
- # Utensils with a wider base or handle and/or cups with wide rubber bases are sturdy and easier to use for patients with paralysis.
- # The patient should not wear nylon or long sleeves. These could catch fire when the patient is near the stove.
- # Always use potholders to keep hands from being burned.
- # Always wear shoes with rubber soles to prevent slipping.

- # Use boards with nails. The spikes can hold fruits or vegetables while the patient either peels or cuts them.
- # Use a high chair with sturdy legs. This will help the patient work at high kitchen counters.

In the bathroom

- # Never let the patient lock the door from the inside.
- # Put rubber mats in the bathroom and make the patient wear shoes with rubber-soles. This will prevent the patient from slipping.
- # Tie soap with a cord to the shower or faucet to prevent it from slipping/falling while the patient is bathing.
- # Place a sturdy stool in the bathroom for comfortable seating. Place a chair in the bathtub so that the patient can transfer without stepping in it.
- # Place the water bucket on a high platform or stool so that the patient does not have to bend.
- # Install a shower-fountain. This will help the patient take a bath while standing.

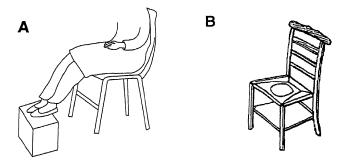


Figure 14. Modified environments: A. Foot-rest. B. Potty-chair.

- # Use a western-style toilet, or modify a chair for toilet use (Fig. 14B).
- # Install a grasp-bar near the toilet for the patient to hold on to. This will prevent him/her from slipping.
- # Install faucets in the house which can be turned on or off with the wrists. Tying wooden pieces to faucets could help.
- # Give the patient a bell which he/she could use to seek help when needed.

HELPING PATIENTS

with

LANGUAGE AND SPEECH DIFFICULTIES

Stroke patients often have problems with speaking and understanding, though they can think well and their intelligence is usually intact.

Most patients know what they wish to say but have difficulty expressing it in words. They can describe functions, but cannot recall the appropriate words. Some patients have problems in using informative words like nouns, verbs, and adjectives; while others cannot use grammatical markers like verb endings, auxiliaries, postpositions, and pronouns. Some patients cannot form appropriate sentence structures.

Some stroke patients with aphasia are verbose and speak well, though what they say does not carry much meaning. There are others who struggle to produce even a sound or word.

In such cases, the family should seek the help of a speech-language pathologist. However, such services are not easily available. Therefore, the best the family can do is to assess communicative strengths and weaknesses of the aphasic patient. This can be done by answering the following questions:

- ▼ How well does the patient speak/understand?
- ▼ Does the patient point to or use correct words/sentences?
- ▼ Can the patient effectively use gestures to communicate?
- ▼ Can the patient read/write?

Once you know the exact nature of the breakdown in language skills, you can help the patient improve his/her ability to communicate. A few communication boards are attached at the end of this booklet, which can be used for communicating with patients who have lost their speech. For a list of specific exercises, the family should consult one of the aphasia workbooks. These are being prepared by this author at present.

Dealing with a stroke patient with aphasia

The following are a few suggestions that can be useful in improving the communicative skills of a stroke patient with aphasia:

- 1. Stress the language functions that the patient already has.
- 2. Comfort the patient by saying that it is alright to communicate in whatever form he/she can or wishes to.
- 3. Be open to the patient's linguistic limitations. Inform those visiting the patient of his/her difficulty in speaking and listening so that they exercise patience and exhibit understanding. Also tell the patient who is visiting him/her.
- 4. You may also write down a message such as the following and leave it next to the patient.

I HAD A STROKE, AND THEREFORE IT IS DIFFICULT FOR ME TO SPEAK, UNDERSTAND, READ, AND WRITE. PLEASE SPEAK SLOWLY AND HAVE PATIENCE WHILE I ANSWER.

This will help those visiting the patient. Keeping this card in the wallet/pocket will help others understand the patient's problem.

- 5. Expose the patient to adequate language stimulation such as interesting radio and television programs.
- 6. Encourage the patient to participate in all situations where he/she is required to speak.

- 7. Stimulate real-life communicative situations in which the family and patient can act out through gestures and facial expressions, and role-playing.
- 8. Promote rhyming, singing and imitating for the patient.
- 9. Ask the patient to speak slowly (no more than 20-25 words a minute) if his/her speech is imprecise or slurred.
- 10. After identifying the area of communicative weakness, develop a specific program of exercises to maintain or improve the patient's communication skills. For specific exercises in comprehending spoken language, speaking, reading, and writing, consult aphasia workbooks or seek help from a speech-language pathologist (if available in your city).
- 11. Patients derive more benefit from therapeutic work if it is systematic and if someone follows their progress. Consistency in time for exercises promotes self-confidence and makes the patient feel secure.
- 12. It is normal if the patient's performance fluctuates from time to time. The patient might be able to retrieve words one day and not another day.
- 13. Aphasics get tired easily and perform better after a rest/nap. Choose that time for working with the patient when he/she is rested and responsive.
- 14. Promote gesturing and simple verbalization in patients who do not speak.
- 15. Patients generally understand better if they are spoken to slowly about simple things.
- Aphasic difficulties can persist for a long time. Therefore, the patient with aphasia should never be considered feebleminded.

- 17. Patients with aphasia follow and communicate better when the conversation involves only two persons. They get confused if more people are around or if there is excessive noise in the background.
- 18. Exposing a patient with aphasia to another patient with aphasia should be encouraging. Unfortunately, there is no national networking of such patients in India. The family is, therefore, strongly urged to look for other aphasic patients in the neighborhood and arrange for monthly or fortnightly meetings of the families. Such meetings not only help the patients but also provide an outlet for spouses of these patients.
- 19. The following cues can be helpful in eliciting words from patients who have difficulty in recalling words or names of objects:
 - a. Asking the name of an object. Say, "What is this called?"
 - b. Direction to state the function of an item. Say, "What do we do with it?"
 - c. Direction to demonstrate the function of the object. Say, "Show me what you do with it."
 - d. Statement of the function by the family. Say, "One writes with it. . ."
 - e. Offering phonemic cue. The family provides the initial phoneme of the word. For example, "k" for "kitaab".
 - f. Supplying the first syllable. The family provides the initial syllable of the word. For example, "ta" for "table".
 - g. Sentence completion. The family provides the sentence without the target word and the patient completes the sentence by supplying the word. For example, "Main. . .parta huun".

Ways for the family to promote communication

- 1. Always talk to the patient, not about him/her.
- 2. Encourage the patient and provide him/her with the opportunity to communicate.
- 3. In the absence of meaningful speech, encourage the patient to use greetings and frequent (automatic) responses. These responses are easier for the patient to speak.
- 4. Perseveration of utterances (repetition of words or actions) is common in the patient's speech. Ignore it. Changing the task may help.
- 5. Ignore the patient's crying. Either continue the task or change it when the patient is crying.
- 6. If the patient is unable to speak, encourage him/her to gesture and write.
- 7. Praise the patient's communicative efforts regardless of how small they seem. Aphasic patients are sensitive to positive reinforcements.
- 8. If the patient is suffering from hemiplegia, encourage him/ her to use the non-dominant hand.

Ways to communicate with a stroke patient

- 1. Listen attentively to the patient.
- 2. Do not interrupt. Allow the patient adequate time to respond.
- 3. Avoid supplying words as soon as you realize that the patient cannot find them.
- 4. Accept all efforts of communication regardless of their significance.

- 5. Speak in a quiet place, free from background noise, such as the television, traffic, and people.
- 6. Control your own verbalizations.
- 7. Speak naturally at a slow rate (not more than 20–25 words a minute).
- 8. Speak at your normal volume. Do not shout.
- 9. Communicate with the patient using:
 - ▼ simple one-clause utterances
 - ▼ familiar nouns and verbs
 - ▼ limited information
 - ▼ gestures, if more effective.
- Communicate when the patient is receptive and not when he/she is tired.
- 11. Make sure you have the patient's attention before you begin talking with him/her.

GLOSSARY

Aphasia impaired ability to speak or understand after

damage to the brain.

Aspiration passing of food or liquids into the airways.

Blood pressure pressure exerted by the blood flow on the

walls of the arteries.

Bolus chewed food mass prepared for swallowing.

Brain a large soft cell mass in the cranium, which

is responsible for the sensorimotor activities and all higher mental functions such as language, memory, thinking, and reasoning.

Contralaterality concerned with the opposite side of the body

as opposed to ipsilateral.

Diabetes a condition characterized by excessive

excretion of urine caused by either hormonal

deficiency or high blood sugar level.

Dominant that half of the brain which takes the lead in

hemisphere processing language.

Dysarthria a speech-related problem that results from

weakness of facial and tongue muscles.

Dysphagia impaired ability to swallow.

Embolism blockage of a small artery by a substance or

clot floating in the blood stream.

Extension movement that straightens a limb.

Flexion movement that bends a limb.

Hemianopsia loss of vision in the left or right half of the

visual field of one or both eyes.

Hemorrhage bleeding from a ruptured artery.

Hypertension condition of high blood pressure because of

constricted blood vessels.

Neoplasm abnormal growth of tissue usually seen in

cancer.

Non-dominant hemisphere that half of the brain that serves spatial-percep-

tual and musical functions.

Pneumonia bacterial inflammation of the lungs.

Presbycusis age-induced hearing loss.

Pressure sores ulceration or irritation of tissues over bony

areas due to pressure from prolonged

confinement in bed.

Spatial and perceptual deficits

impaired ability to recognize the organization

of objects in space.

Stroke interruption in blood supply to any part of

the brain.

Thrombosis gradual formation of localized clots that

block the artery.

Transient Ischemic

Attack

temporary interruption of blood circulation characterized by symptoms which last for up

to 24 hours.

Videofluoroscopy radiographic study of the barium-laced bolus

as it passes through the mouth and throat.

POCKET CARDS

Carrying these wallet/pocket cards can help individuals with aphasia to communicate with others.

I had a stroke, and therefore it is difficult for me to speak, understand, read, and write. Please speak slowly and have patience while I answer your question. Do not shout. Try to understand my words and gestures. Ask me yes and no questions.

My name is
I live at
My telephone number is
Check those that apply to the person with aphasia
Speaking is difficult.
Speaking takes more time.
Understanding is difficult.
Understanding takes more time.
Writing simple words helps.
Follow my gestures.
Please communicate with gestures.

MAJOR REGIONAL MEDICAL CENTERS with NEUROLOGICAL AND REHABILITATION SERVICES IN INDIA

EAST

- 1. Bangur Institute of Neurology, Calcutta, West Bengal.
- 2. Institute of Neurology, Dispur, Guwahati, Assam.
- 3. Medical College Hospital, Guwahati, Assam.

WEST AND CENTRAL

- Central India Institute of Neurological Sciences, Nagpur, MP.
- Choithram Hospital, Indore, MP.
- 3. M.G.M. Medical College and M.Y. Hospital, Indore, MP.
- 4. J.J. Hospital, Mumbai, Maharashtra.
- 5. Jaslok Hospital, Mumbai, Maharashtra.
- 6. Medical College Hospital, Baroda, Gujarat.
- 7. Nair Hospital, Mumbai, Maharashtra.
- 8. S.M.S. Medical College Hospital, Jaipur, Rajasthan.

North

- 1. All India Institute of Medical Sciences, New Delhi.
- 2. Christian Medical College, Ludhiana, Punjab.
- 3. G.N.D. Hospital/Govt. Medical College, Amritsar, Punjab.
- 4. Govind Ballabh Pant Hospital, New Delhi.
- 5. G.S.V.M. Medical College, Kanpur, UP.
- 6. King George's Medical College, Lucknow, UP.
- 7. L.L.R. Medical College, Meerut, UP.
- 8. P.G.I. Chandigarh, Union Territory.

- 9. Ram Manohar Lohia Hospital, New Delhi.
- 10. Safdarjung Hospital, New Delhi.
- 11. Sanjay Gandhi Medical Institute, Lucknow, UP.
- 12. Sher-e-Kashmir Institute of Medical Sciences, Srinagar, J&K.

SOUTH

- 1. Apollo Hospitals, Chennai, Tamil Nadu.
- 2. Andhra Medical College, Vishakhapatnam, AP.
- 3. Madras Institute of Neurology & Government Hospital, Chennai, Tamil Nadu.
- 4. MS Ramaiah Medical College Hospital, Bangalore, Karnataka.
- 5. National Institute of Mental Health & Neurosciences, Bangalore, Karnataka
- 6. Nizam's Institute of Medical Sciences, Hyderabad, AP.
- 7. Sri Chitra Tirunal Institute of Medical Sciences, Trivandrum, Kerala.
- 8. Madurai Medical College and Rajaji Hospital, Madurai, TN.
- 9. Coimbatore Medical College, Coimbatore, TN.

For a list of speech-language pathologists or audiologists practicing in your city, write to the Secretary, ISHA, All India Institute of Speech and Hearing, Manasgangotri, Mysore 570006.

To obtain the list of physiotherapists and occupational therapists in your city, write to the Rehabilitation Council of India, 4 Vishnu Digamber Marg, New Delhi 110002.

Delhi.

ıcknow, UP. ıl Sciences, Srinagar,

ladu. atnam, AP. overnment Hospital, ital, Bangalore,

& Neurosciences,

25, Hyderabad, AP. .cal Sciences,

ji Hospital, Madurai,

batore, TN.

gists or audiologists tary, ISHA, All India 30tri, Mysore 570006. occupational therapists ncil of India, 4 Vishnu

मुझे सुनाई देता है				में	मैं जो व इन शब्दों	हूँ उसे में की सहाय	कृपया को बुलाइये				
यह ये इस इन वह वे उस उन में मुझे हम हमारा हमारी तुम तुम्हारा आप मेरा मेरी कौन किस कैसे क्या कहाँ कब जब जो जिस जिसे जिन जिन्हें जहाँ से का की को				ता रहा गा गे गं यी थी देख भेज लिख बोत	ये पसन ना ला खा रख	ा रख पूछ सोच		ा पी क	सब को हमेशा जैसे कुछ इसलिये क्योंकि लेकिन पर तक अन्दर बाहर ऊपर नीचे बाद में पहले भी सिर्फ जल्दी इधर उधर यहाँ वहाँ घर आगे पीछे के साथ के लिए बहुत यदि सामने कम ज्यादा		
- अ क ट	आ ख ठ	<u> </u>	ई ग ड	उ घ	ऊ च	ए ढ	एँ छ	ओ ज ढ़	औ झ ण	1	
त	থ	द	ध	न	प	फ	ब	भ	म्	बीमार घड़ी पत्र पानी कमरा	
य	ŧ		ल	7	1	स		श	ह	घर कुर्सी साबुन दवा रूपये	
0	1	2	3	4	5	6	7	8	9	पैसे गरम ठंडा परिवार	
	इतवार सोम	बुध	शुक्रिया			कृपया अभी व्यस्त फिर बोलिये		माफ कीजिये, मैं बहुत परेशान हूँ			
बृहस्पति शुक्र शनि			माँ लड़का	, ,		नया शब्द वाक्य		- नमस्ते बैठिये			
मेरा न	नाम		है मेरा पता है					हाँ नहीं शायद			
कृपया धीरे बोलिये				अच्छा बुरा ठीक						PF117 191 19	

पिताजी	माताजी	बेटा	बेटी	भाई बहन	डाक्टर	पति पली
	- 0					
बुशो हैं	दुर्खी नहीं	बीमार	च्यादा →	कम ↓	नमस्ते 🔐	चाय 🕌
₽ (1)	खना अ	पानी रिट	чя <u>Пы</u>	§#Í A	यही	वस्मा
विस्तर	रेलेफोन	रेलीवजन	कमीज	पेर	जूता	ज ()
अ। (चे)	ē O		पढ़	чег	ul A	बैठ
ख िय	पका	पो सि				

After reading this book, you will be able to understand why stroke patients cannot express and do things physically. We hope that your awareness of the limitations of your loved one will lead to an increased appreciation of life and familial closeness. Further, it will help you to create a safe environment in the house and provide the best short- and long-term care to the patient.

We hope that we have succeeded in our efforts to answer your queries about stroke and aphasia.

What is aphasia?

Aphasia is a communication disorder resulting from damage to the brain A person with aphasia is able to perform intellectual functions like thinking and reasoning but his/her ability to speak, understand speech, read, or write are imparied.

What causes aphasia?

Stroke is the most common cause of aphasia. It can affect anyone regardless of age, sex, or socioeconomic status. However, aphasia can also result from head injury, brain tumor, and other brain diseases.

What is stroke?

Stroke is an interruption in the blood supply to any part of the brain due to narrowed, blocked, or ruptured arteries. This deprives a part of the brain of required oxygen and nutrition and, as a result, the affected brain cells die. The effects of stroke are sudden and characterized by paralysis of the limbs, loss of sensation in one half of the body, blindness, and disorders of language and speech.

How can you help a stroke patient?

Educating yourself about the causes of stroke and its effects on the patient's physical ability and communicative skills can help you support his/her efforts to become independent. Treating patients with respect and refraining from criticizing promotes their self-confidence.

Can stroke and aphasia be cured?

There is no medication to cure stroke and reverse its effects on the patient's physical ability and communicative skills. Only rehabilitational training and teaching of compensatory skills can minimize the impact of brain injury.

Can stroke be prevented?

Stroke can be prevented if appropriate steps are taken early in life. For example, cutting down on dietary fat and cholesterol, exercising regularly, getting your blood pressure checked regularly, and seeking medical treatment for heart-related diseases.

Raina Sagar